

North Dakota Real Choice Systems Change Grant Rebalancing Initiative

A Summary of Focus Groups and Personal Interviews Conducted in North Dakota

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During October, November and December of 2005, a series of statewide focus groups and in-home personal interviews were conducted.

This research was conducted to identify current perceptions, patterns, themes, and suggestions for improving the choice and self-direction, quality and access to long term care supports, (i.e. home and community based services and nursing home care) for the elderly and persons with disabilities.

Combined, a total of forty-three focus groups and personal interviews were conducted throughout the eight human service regions in both rural and urban communities of North Dakota.

Focus group participants included:

- consumers of home and community based services (HCBS)
- elderly nursing home residents
- younger nursing home residents
- family members of consumers of continuum of care services
- providers of continuum of care services.

This research was also conducted to identify ways to develop a mechanism to balance state resources for services, and to identify elements for the design and structure of a single point of entry mechanism for all long term care supports for the elderly and people with disabilities in North Dakota. Through this process and the information gathered, the grant will build a plan that reflects the needs and concerns expressed by the public.

Common Cross-Group Themes Expressed by North Dakotans

Cross-group themes include the common patterns that have emerged across all focus groups conducted.

North Dakotans currently find out about continuum of care services through:

- social workers (including hospital, nursing home & county)
- doctors and hospital staff
- word of mouth
- on their own
- family members

"Had it not been for maybe some neighbors of mine that used some of the services, I would have never known that they existed." Family member

Common problems regarding continuum of care services

- confusion of information
- high cost of services
- lack of information
- no choices available for services
- lack of flexible funding to support consumer's choice of services

"There are good, qualified, trained people, who are very helpful; unfortunately most of us don't even know where they are." Family Member

"I took care of my wife for 16 months and at that time I had to do everything, I did all the cooking, cleaning, all of the wash, dressed her, cleaned her up, took her to her appointments and I didn't know where to turn I didn't know where I could get some help." Family Member

"It would be helpful if there were someone there that could tell you rather than send you on again because that happens so often too. You get to one place and then you go there and then you have to go over there." Elderly Nursing Home Resident

"My mother would be home right now if I could afford the \$8/hour for someone to watch her. But yet I couldn't get the funding to keep her at home. Because [Medicaid] will pay to put her in a nursing home but they won't pay to keep her at home, when it would not cost them nearly as much." Family Member

Other common problems identified include:

- living in a rural community, isolated from services that are not available
- no needed services available
- not eligible for needed services
- not enough workers available to provide the needed HCBS

Common needs regarding continuum of care services

- case management described as assistance with assessment, care planning, provider selection, monitoring services, and making referrals
- both functional and financial assessment
- a reliable, consistent, and knowledgeable "go to" person
- a single point of entry system for streamlined access to services, a simplified service system
- access to comprehensive, timely information about services
- home and community based service options
- public education related to continuum of care services available and preventative education
- flexible funding to pay for the service of choice
- alternative housing options

"I want[ed] one voice that was nice and that would give me the same answer twice to the same questions and know what they were talking about." Family Member

"They[case management] need to be knowledgeable about what's out there so that they can give you the appropriate information in a great timely manner and say, okay you have this option, this option,[and] this option." Consumer of HCBS

"Assisted Living or self assisted living, I think Medicare [Medicaid] should help pay for things to keep you in the home instead of the nursing home and expenses would be a lot less. And at home it's better I think." Younger Nursing Home Resident

"We need a place where we can find the services that the person needs, preferably a handicapped person [to help us] who knows about all these things... They [case managers and consumers] need a place that you can sit down and talk and show them [case managers] what you've got and they have a look at your house and see if there are any problems with it, fix your house and find out what's right for you." Younger Nursing Home Resident

"If you look at how health care is delivered today,...it is driven by payment systems rather than for assessment with goals for patient management...and so what are we doing, we aren't taking care of patients we are doing assessments for billing...When you step back, man this thing is broken. We are all doing our own thing and nobody is communicating." Provider

Consumers of continuum of care services expressed what is important to them:

- the opportunity to stay at home
- the opportunity to live with or near family
- the opportunity to maintain independence

The Focus Group & Personal Interview Final Report is available at:
<http://www.nd.gov/humanservices/info/pubs/ltccontinuum.html>

"You'd be surprised what little bit of care you could get in your home would make your life [easier], so much as an hour a day makes such a difference. I have three hours of help during the week and it just means the world to me." Family Caregiver